

PUBLIC PARTICIPATION

Monday, May 24, 2004

WTC Expert Technical Review Panel

Response to Panel's Request

- This presentation is the result of a community meeting held (05/21/04) to respond to the WTC Panel's request (05/18/04).
- Dr. Jeanne Mager Stellman was invited to attend in response to the panel's assignment.
- This presentation is a rapid first response to the WTC Panel's request.

The World Trade Center Community: Who We Are

- The public concerned is defined as the public affected by, or having an interest in, the environmental decision-making.
 - *United Nations Economic Commission for Europe, AARHUS Convention: Convention on Access to Information, Public Participation in Decision-making and Access to Justice in Environmental Matters,*
<http://www.unece.org/env/pp/contentofaarhus.htm>

Community can be characterized by the following ways:

- Even after 9/11, Lower Manhattan is the third largest “city” in the country
- Diverse Stakeholders
 - Residents: all incomes and nationalities
 - Students
 - Downtown workers and their union representatives
 - Commuters
 - Ex-downtown residents and workers and students

The Current Process

- Ex Officio Panel Member (one Community Liaison)
- Right to Make Public Comment
- Open meetings & non-systematic postings of meeting summaries
- No formal method for systematically assuring community input into design, execution, analysis and communication of proposed study

Issues to be addressed- Public Commentary

- The broader public has not been systematically alerted to the meetings.
 - Thus, participation is largely limited to the community we “know.”
 - Broader community participation would help ensure that the interests of all stakeholders are addressed.
- Significant time reduction in public comment (25%).
- Inadequate process for assuring that public comments are accurately recorded and summarized.

This Public Comment Process can be improved significantly

- Informing the Public in a timely and effective manner of
 - Agendas
 - Proposals
 - Panel Meetings (publicized in advance so it can be posted on community calendars)
 - Transcripts/minutes posted before next meeting
- Using E-dockets (online public docket & comment system), link to from EPA web site and use it
- Avoiding Conference Phone Calls

Development of Formal Input to Study: Community-Based Participatory Research Protocol

- Community-Based Participatory Research (CBPR) is a well-established method for involving affected communities in rigorously designed and executed research projects.
- CBPR will meet the need to expand the Community Process by formalizing the input of the community.

CPBR Is Not A New Concept

- Some examples are:
 - Northern Manhattan Asthma Studies
 - Community Action Against Asthma (Detroit)
 - US EPA Cumulative Exposure Project (Greenpoint/Williamsburgh NY)
 - NIEHS Translation Research Program
 - Agency for Healthcare Research & Quality initiatives
- (<http://www.ahrq.gov/about/cpcr/cbpr/cbpr1.htm>)

CBPR meets U.S. EPA Goals

- Public Involvement Policy issued in June 2003. “The Policy’s overall goal is for excellent public involvement to become an integral part of EPA’s culture, thus supporting more effective Agency decisions and actions.”
 - *“How to Improve Public Meetings and Hearings”*
(EPA 233-F-03-012)

Purposes, Goals and Objectives of this EPA Policy

- “Effective public involvement will make it easier for the public to contribute to the Agency's decisions, build public trust, and make it more likely that those who are most concerned with and affected by Agency decisions will accept and implement them.”

<http://www.epa.gov/publicinvolvement/policy2003/policy2003.pdf>

Agency for Healthcare Research & Quality

- “The exclusion of communities from the research process has implications for research and practice. Interventions have often not been as effective as they could be because communities were not involved. Because communities were not included in all aspects of intervention design, implementation, and evaluation, interventions have not been tailored to participant concerns and cultures.”
 - Dr. Barbara Israel,
<http://www.ahrq.gov/about/cpcr/cbpr/cbpr1.htm>

Principles of CBPR as a Tool to Advance Environmental Health Sciences

- Promotes active collaboration and participation at every stage of research
- Fosters co-learning
- Ensures projects are community-driven
- Disseminates results in useful terms
- Ensures research and intervention strategies are culturally appropriate
- Defines community as a unit of identity
 - “community ultimately be defined by the people whose health is most likely to be affected by the research.”

O'Fallon & Deary, Environmental Health Perspectives, 11 S2,
April 2002

CPBR and the WTC Panel

In order for the “community” to collaborate, a formal mechanism by which the community can have input into:

- Conceptual framework of study
- Specific hypotheses
- Design (choice of areas to be sampled & substances to be assayed)
- Execution of protocol
- Analysis of results
- Policy implications

Conclusions

- CBPR is a complement to -- not a substitute for -- Public Comment
- The Community needs to be part of a CBPR process:
 - To ensure that the research conceptualization, design and execution are reflective of community needs and acceptable to the community
 - To facilitate community participation in the process
 - To facilitate that, when a goal is reached, the community will trust the results

Conclusions

- A mutually agreed upon expert in CBPR needs to be immediately engaged to formalize the CBPR process
- Resources need to be made available to the community so that it can participate in CBPR in a meaningful way
- The Community wants to make very clear that it is not interested in expediency at the expense of a scientifically valid attempt to find out what WTC contamination remains

Identification of Buildings Committee

- Potential Candidates for Sampling Program will come through two ways:
 - Effective Outreach
 - Use of Community-Based Participatory Research (CBPR)